The future of UK syringe exchange

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Syringe exchange has been a cornerstone of HIV prevention strategies for people who inject drugs. It has been one of the most rapidly expanding and developing areas of work, and has had major significance as a symbol of new aims, working practices and working ideologies for those seeking to help drug users reduce their risk of HIV infection or of transmitting it to others. Programmes in Britain, Australia and the Netherlands have received international attention and have been held up as models for HIV prevention elsewhere.

The first syringe exchange schemes in Britain were established in 1986, with a major take-off with the government sponsored pilot experiment which ran from 1987 to 1988 (Stimson et al 1988).

Syringe exchange has now moved into a second phase. This has been marked by rapid expansion of the number of sites, with about 120 schemes in England by the end of 1989 (Lart & Stimson 1990). Exchanges operate, with less success, in Scotland. A programme is now starting in Wales.
Much of the publicity about syringe exchanges focused initially on the large special purpose schemes which were set up specifically to run this service, such as ‘The Exchange’ at Cleveland Street and the ‘Caravan’ at St Mary's Hospital, both in London, and the Mersey Regional Drug Training and Information Centre in Liverpool. Our recent survey of schemes shows that the special ‘stand alone’ schemes are rare. Most in fact operate from preexisting drugs agencies. The dominance of drugs agencies in HIV prevention is a theme we shall return to. There are a few schemes run in collaboration with high street pharmacies, and from a variety of other health facilities such as genito-urinary clinics. We estimate that one million syringes were distributed from 55 syringe exchanges in 1988-9.

Syringe exchange is now an accepted part of the UK response to the prevention of HIV transmission among people who inject drugs, with ministerial and departmental support, and support from many drugs workers. Indeed, one remarkable feature is how readily the strategy was adopted and how it received so little political, community or professional opposition. We will attempt to explain this ready acceptance later. The situation has not been the same in some other countries notably the United States of America. The contrast with the UK is extraordinary: in the USA the only schemes to run with of official sanction or acquiescence are in Portland, Boulder, Tacoma, and New York. There are guerrilla schemes in San Francisco and New England. The New York scheme has now been closed by the Mayor of New York.

This second phase of syringe exchange in the UK is marked by a shift from the ‘frontier spirit’ of those who in the early days thought that they had discovered new ways of working with drug users, to the hard slog of ‘getting on with business’. It has moved from an initial urgency to sell the message about this new service, to a need for fine tuning of the service. We are now in the position of having the luxury to discuss this fine-tuning. Many countries with major problems of injecting drug use have not yet reached the take-off stage. Syringe exchange has major potential to help reduce the spread of HIV. But the promise of the syringe exchange strategy hides its limitations. As we move into the second phase of syringe exchange it is time to analyse critically its contribution and future potential. The question that this paper will raise is whether this is just a matter of fine tuning, or whether it demands a rethinking of the strategy.

Achievements

First the achievements. A remarkable feature of the syringe exchange experiment is the fact
that it has been extensively documented, monitored and evaluated, and that its workers have agreed to have their work scrutinized. No other area of drug work that has received such critical attention, and few of us would allow our work to come under such examination. We know that syringe exchanges are successful at a number of measures. They are good at reaching people who might not be reached by more conventional drugs services. They attract people who are motivated to make changes in their behaviour. They are able to deliver the service - getting syringes out and getting them back. Many also offer a lot more to clients in the way of advice and counselling, practical help with housing, finances and the law, very basic health care, and referral on to other helping and treatment agencies. As a worker in one of the agencies put it: 'we are not just a syringe exchange' (Donoghoe et al, 1989a; Stimson, 1989; Carvell & Hart, 1990).

There is considerable evidence that those who attend exchanges are helped to achieve and maintain lower risk behaviour. The Monitoring Research Group has conducted numerous studies of clients of syringe exchange schemes, and of comparison groups of injectors not attending such schemes. In all we now have HIV risk behaviour data on over 4,000 people since 1987. The various studies show a consistent decline in self-reported sharing, which has been triangulated by interviews in different settings, using a variety of interviewers (both professionals and ex drug users), using a range of questions, in a number of locations in England, Wales and Scotland. In 1987 the percentage reporting sharing syringes in the last four weeks was around 28% at intake for syringe exchange attenders, and 60% for others. In 1989 the rate for attenders had dropped to around 21%, and for others a major drop to 32%. All reports from interviews suggest that lack of syringes is now a less common reason for sharing syringes. These changes are of major importance.

Syringe exchanges have a clear role to play in HTV prevention, but moving into their second stage of development we can identify several limitations. The Monitoring Research Group has continued to monitor exchanges, and we can now look at how syringe exchanges have developed since the first evaluation that was conducted between 1987-88.

Data from 1989 and 1990 show that they continue to attract clients, but the number of clients coming to individual exchanges is, on average, disappointingly low. Of 55 exchanges surveyed in 1989, the average number of clients per week ranged from 1 to 150, with an average of 21. In 1987-88 we found that exchanges tended to attract older, longer term injectors, and that proportionately few were women. Many exchanges are well aware of this, and have made creative attempts to change it. But that client profile remains substantially unchanged. There has been no improvement in their ability to reach younger injectors, newer recruits to injecting, and women. Syringe sharing rates are reducing, and self
reported sharing is lower than it has ever been. But there remain substantial numbers who continue to share. For example, even with the lower sharing rates reported in 1989, we still find that 21% of syringe exchange clients had shared syringes in the past four weeks, with an average of 1.7 different partners, for those who shared (Donoghoe et al, 1990).

Limitations

What are the current limitations of the syringe exchange strategy? There are several areas that are relevant. The first is a question of resources available to agencies, their capacity, and the potential demand for the service.

To examine these issues we need to make certain assumptions about the prevalence of injecting drug use. Estimating the prevalence of injecting is more difficult than estimating how many pigeons there are in London (as one of my colleagues put it - 2"a pigeon is obviously a pigeon and can't hide the fact, a drug injector can and often will hide the fact"). But innovative work in the 1970's, often using methods adopted from the study of animal populations, have helped refine our estimates. Using data from these 'drug indicator projects', and from informed expert assessments from different parts of the country, the consensus of the Advisory Council on the Misuse of Drugs working group on AIDS and Drug Misuse estimated that there were between 35,000 and 75,000 drug injectors in England in 1986, and that figure will be used in this paper (ACMD, 1988). Many would dispute this figure, but other estimates can easily be used in what follows.

What of the adequacy of current distribution of syringes? Extrapolating from the Monitoring Research Group survey of syringe exchanges would indicate that about two million syringes would have been distributed from syringe exchanges in 1989/1990. People who inject drugs can also buy syringes from some pharmacists, and the number of pharmacists willing to supply syringes has increased in the past two years. Glanz's survey of retail pharmacists suggests an additional two million syringes from those outlets (Glanz et al, 1990). Assuming that there are between 35,000 and 75,000 injectors in the UK, and that they each need a sterile clean syringe per day, then between 13.5 and 27 million syringes would need to be distributed each year. Current distribution falls far short of this.
What is the capacity of the agencies? If we assume that each current injector would visit a syringe exchange every two weeks, there would be between 17,500 and 37,500 visits per week. With 120 syringe exchanges this is a client load of between 149 and 312 per week. In practice, those agencies currently running syringe exchanges see an average of 21 people a week for syringe exchange. (A few large agencies such as Bristol Drugs Project or the Community Drug Project in London see a total of about 100 to 120 clients a week for all services.) Capacity would thus have to increase seven to fifteen times to meet this caseload.

Assuming that every drugs agency in England ran an exchange, and there are estimated to be 300 currently (1989) funded agencies in England, then the client load would be between 58 and 12: each, just for syringe exchange. However, drug agencies operating walk in day centres in England (the nearest equivalent to syringe exchange) see an average of only 6 clients per day (McGregor et al, 1990). Another way to look at this is to consider the number of staff required. Drug agencies in England see an average of one client per staff member per day. Between 3,500 and 7,500 staff would be needed for 35,000 to 75,000 injectors to visit once every two weeks.

The second relevant area is the relationship between syringe distribution and changes in risk behaviour. In the first phase a simple message has been promoted - don't share syringes - along with the means to avoid sharing - supplies of sterile syringes. The evidence is now quite considerable that this strategy is working to help injectors change their behaviour. But the changes are not enough. Indeed, given the percentage who still report sharing syringes, it is surprising that HIV prevalence has not changed dramatically.

On the plus side it is clear from our qualitative studies that sharing syringes is no longer viewed as the norm and that most people who inject drugs try to avoid sharing syringes. It is also clear that ensuring a good supply of clean syringes is a necessary measure, but not sufficient to ensure that sharing will not occur. Let us take for granted that most injectors know the health message, and that syringe supply has improved. This in itself is not sufficient to ensure that sharing does not occur. Last year Jill Burt conducted a qualitative study of drug use in London and Brighton. People in that study had adopted a variety of protective strategies to avoid the risk of HIV infection. They talked about sharing as if it were no longer part of the etiquette of everyday drug use. Syringe sharing did however occur, but these occasions were described as exceptional events which prompted justificatory explanations. Sharing occurred for a variety of reasons, such as running out of syringes at times when supplies could not be obtained, being away from home without syringes, a syringe breaking, or being intoxicated (Burt & Stimson, 1989).
The other area is sexual behaviour. Here there is less room for optimism. Most people who inject drugs are sexually active. Half of those who are active have partners who themselves do not inject drugs (Donoghoe et al, 1989b). Condom use is uncommon. A surprising percentage are pregnant itself a sign of unsafe sex. In our interviews with and observations of staff at syringe exchanges it has become clear that both staff and clients find it difficult to talk about sex. Because syringe exchange is located in drugs agencies, the dominant 'frame' is drug use and this discourages talk of sexual behaviour. We first noted this in 1987 and have little evidence that the situation has changed.

Drug agencies have responded to these twin obstacles of the limited resources and limits to changes in risk behaviour in two main ways. The first is to try to reach out to more drug injectors through, for example, mobile schemes and outreach work, and involving local pharmacists. The second is to use contacts with clients to engage them in counselling in safer sex and safer drug use. For example, syringe distribution can be supplemented by instruction in a variety of other protective strategies. This would include advice on syringe hygiene (ie cleaning syringes), how to avoid risky situations, preferred places to inject drugs, promoting social skills in refusing sharing and promoting use of sterile syringes, and instruction in safe disposal. The drawback is that both outreach and counselling are extremely labour intensive.

Facilitating and constraining factors

Understanding the limits of the syringe exchange strategy requires an understanding of the factors that have facilitated the original development of schemes. It is our thesis that the factors that helped syringe exchange develop so rapidly, are now the features that limit its development. Therefore, we need to look at why drugs agencies have been so prominent in the development of this strategy.

Why did syringe exchange develop so rapidly and relatively easily in England? There are three important linked factors. The first is what we call the discourse on harm minimization that developed in many drugs agencies in the eighties (and can itself be traced as one important
theme of the British approach to drug problems from earlier periods). Throughout much of the
last seventy years of British drugs policy there have been medical advocates of what would now
be described as harm minimization (although they may not have employed this term). For
example, the debate on prescribing drugs to addicts, dating from the 1920's, included claims
that prescribing drugs to which people are addicted enables them to lead relatively normal
social lives. The notion that harm can be limited was certainly there in the 1960's in both
professional and drug user circles. And it has been part of the workplace rhetoric in many
statutory and non

statutory agencies in the early 1980's.

The second factor that facilitated syringe exchange is a matter of institutional sites. By the time
HIV became an important issue for drug injecting, there was a wide range of agencies, mainly
outside of the medical arena, involved in the provision of help and advice to drug users. For the
most part these agencies were established from 1984-85 under the Department of Health and
Social Security Central Funding Initiative which pump-primed almost one third of drug services
and contributed funds to almost a half. Three quarters of currently existing drug services in
England began operation between 1984 and 1989. This initiative increased accessibility of
services and drew in new client groups. When HIV and AIDS became important issues these
agencies were able to adopt HIV prevention work and adapt their work to cope with the new
tasks. As Ettorre has described it- "One clear benefit of the CFI promotion of the new services
was that it provided a base from which AIDS work could be developed and allowed a smoother
and more rapid response to this major public health issue than might otherwise have been the
case."

The third factor that influenced their development is the social policy framework. English drugs
policy in the 1980's has been characterised by central policy and funding initiatives, but with
high levels of local autonomy. This absence of central direction and coordination has resulted in
a proliferation of different agencies which are responsive to local needs.

Without these three factors it is unlikely that syringe-exchange would have been so readily and
rapidly adopted in this country. They also explain why HIV prevention for injecting drug users
has developed primarily as a client oriented service operating from drug agencies. In other
words, it has been added on to preexisting drug services with a preexisting idea of
harm-minimimization through individual client contact.
This combination of a discourse on harm minimization, institutional sites and policy framework can also inhibit developments. The fundamental question is whether HIV prevention can be adequately managed through existing services.

Public health and community change

One of the practical developments that is needed is an increased supply of syringes and a corresponding increase in opportunities for safe disposal. This cannot be achieved through individual based services alone, for drug services can never reach sufficient people. It must be done through a proliferation of different outlets including pharmacies, outreach and secondary distribution and, to some extent, the separation of syringe supply from disposal. There is also an urgent need to promote syringe hygiene, and to develop a broader conception of safer drug use which recognises a range of protective strategies.

But more fundamentally it is time to begin to rethink the aims of the approach. HIV prevention is about promoting healthy behaviour. But health behaviours do not occur in a vacuum. Health behaviours - and risky practices - are located within social, economic and cultural practices. There are good reasons why people engage in harmful practices. Whilst we can attempt to tackle these behaviours on an individual client centred basis, what has to change is the broader culture within which drug use - and syringe-sharing and sexual behaviour- take place. Promoting healthy behaviour is thus a massive task of encouraging social change. We need then to think not so much how we will help this individual to change - and the individual may continue to be the vehicle of change but how through that person we can help others - whom we will never meet to change. That is a public and community health task.

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Donoghoe, M.C., Stimson, G.V. & Dolan, K., 1 989b, Sexual behaviour of injecting drug users and associated risks of HIV infection for non-injecting sexual partners. AIDS Care 1,1, 51-8


